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Exploring the Experience of Young People With Chronic Fatigue Syndrome/Myalgic Encephalomyelitis and Depression Using Qualitative Methodology

Contributors: Anna Kathryn Taylor, Amberly Brigden, Maria Loades & Esther Crawley

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Abstract

This case study provides an overview of our experience of conducting qualitative interviews with young people with chronic fatigue syndrome/myalgic encephalomyelitis and co-morbid low mood. We interviewed young people with chronic fatigue syndrome/myalgic encephalomyelitis and low mood to gain insight into their views of the relationship between their fatigue and low mood, why they felt they developed low mood, the impact of illness on their lives, and treatment strategies they found helpful or unhelpful. In this case study, we outline our methods and results; discuss our specific methodological strengths, such as including young people in research design; and illustrate the ethical issues involved in interviewing this patient group. We also describe some of the challenges we encountered, such as difficulty recruiting. Finally, we outline some general recommendations for conducting interviews with young people (alone and with parents) and comment on some specific suggestions for mitigating the challenges we encountered.

Learning Outcomes

By the end of this case, students should be able to

- Describe the value and process of using qualitative methodology
- Summarize the issues involved in interviewing young people with and without parents present
- Explain how symptoms such as fatigue and low mood present challenges to recruitment and interviewing, and how this can be mitigated
- Illustrate how novel interview techniques, such as utilizing Skype, can be beneficial

Project Overview and Context

Pediatric chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME) has a prevalence of 0.4% to 2.4% (Chalder, Goodman, Wessely, Hotopf, & Meltzer, 2003; Crawley, 2014; Crawley, Emond, & Sterne, 2011). It is defined as “generalised fatigue persisting after routine tests and investigations have failed to identify an obvious underlying cause” that must limit physical functioning, and young people must also have at least one other symptom such as headache, sleep disturbance, or joint pain (National Institute for Health and Care Excellence [NICE], 2007; Royal College of Paediatrics and Child Health [RCPCH], 2004).

Mood disorders are common in young people with CFS/ME, with approximately one-third suffering from probable clinical depression (Bould, Collin, Lewis, Rimes, & Crawley, 2013; Carter et al., 1999; Garraalda, Rangel, Levin, Roberts, & Ukoumunne, 1999; Smith, Martin-Herz,

Womack, & Marsigan, 2003; van Middendorp, Geenen, Kuis, Heijnen, & Sinnema, 2001). Young people with co-morbid CFS/ME and depression are typically more disabled, and experience more significant pain and fatigue, than those without depression (Bould et al., 2013). However, little is known about why low mood develops or what treatment may be helpful (Loades, Shiels, & Crawley, 2016).

Our study used qualitative interviews to explore the experiences of young people with CFS/ME and depression. We hoped to understand their views on why their low mood developed, their perception of the relationship between their fatigue and low mood, the impact of illness on their quality of life, and what they had found helpful or unhelpful in treatment.

In this case study, we will discuss our experience of conducting qualitative interviews with young people with a chronic disease and co-morbid depression, describing how we included young people in the development of the study, and the specific challenges and complexities of interviewing young people. We will comment on what we did to mitigate these challenges and offer suggestions that can be utilized in other research projects.

Research Practicalities and Design

Our study was run by the University of Bristol and recruited participants from a specialist pediatric CFS/ME service in Bath, which provides NICE-recommended treatments (Activity Management, Cognitive Behavioral Therapy [CBT], and Graded Exercise Therapy).

Identification of Participants

Young people were eligible for the study if they were aged between 12 and 18, had a diagnosis of CFS/ME (NICE, 2007), and had co-morbid low mood. The latter was defined as a depression subscale score of >9 on the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), either at assessment or at a subsequent treatment appointment. The HADS is a 14-item questionnaire developed to measure symptoms of anxiety and depression in a general population and has been validated for use in adolescents. Young people were excluded from the study if they were housebound and unable to attend outpatient appointments. Participants were recruited at follow-up appointments with their clinician.

Consent

Because of the age of the participants, we put into place a rigorous two-step consent process: potential participants were given a Participant Information Sheet and asked to complete a "consent to contact" form. At least 24 hr later, they were contacted by a researcher and given the chance to ask any questions about the study before an interview was arranged. They were

required to complete a full study consent form prior to the interview. Participants aged between 12 and 15.99 were asked to give assent, whereas their parents provided consent. Participants aged above 16 were able to consent for themselves. Participants were made aware that the interview would be recorded and that anonymized quotes would be used for the publication. They were told that they could withdraw from the study at any time. Throughout the recruitment and interview process, young people could ask questions about consent, or more generally about the study, at any time.

Interview Structure and Questions

A semi-structured approach was used for the interviews, which uses a topic guide (a list of open-ended questions) to ensure that important areas are covered in the interview, but is flexible so the interviewer can follow additional lines of discussion if they arise. Young people completed a HADS questionnaire prior to the interview, and the first part of the interview was framed around the person's experience of CFS/ME and their responses to the HADS questions. We started with relatively concrete and familiar questions with the aim of accustoming participants to the interview process and making them feel comfortable. Based on this foundation, the interview progressed to more open questions requiring more introspection and reflection, and by that point in the discussion, the young people were more at ease with the interviewer and the situation. This included questions about their development of and experience of CFS/ME, why they felt they had become low in mood, whether the low mood preceded or followed their fatigue symptoms, factors contributing to low mood, and what treatment strategies they had found helpful or unhelpful. The semi-structured approach enabled a flexible interview and the potential to follow different lines of discussion and incorporate these into future interviews.

Terminology

Terminology and illness labeling often vary within patient groups. Some young people called their CFS/ME "CFS," "ME," or simply "fatigue," whereas they labeled their low mood as either "depression" or "low mood." We therefore commenced each interview by asking the young person what they called their symptoms and what they wanted the interviewer to refer to them as during the discussion. This aimed to make sure that young people felt listened to and respected in how they wished to talk about their illness.

Interviews

Eight of the nine interviews were conducted at the participant's home, and one interview was conducted on the telephone. This was done not only for the comfort of participants who may be nervous but also for their convenience; some participants lived in rural locations with little public

transport while the researcher could drive to interview them. The interview conducted on the telephone was done this way due to the distance the participant lived. Of the interviews conducted at home, the majority were carried out in a communal area such as a living room or dining room according to participant choice. One was conducted in a participant's bedroom due to her being unwell that day. Participants were given the choice of whether to be interviewed alone or with a parent in the room. Six young people were interviewed alone, and three with a parent present.

Ethical Concerns

Safeguarding was a crucial issue due to the ages of the participants, their disability, and potential risks associated with having both CFS/ME and low mood.

In terms of the physical burden, we ensured that interviews would not last longer than 30 min without checking with the participant that they were happy to continue. Young people who were severely affected by CFS/ME were excluded from the study, and for those who were mild/moderately affected, a 30-min interview would fall within their time recommended for activity. The burden of involvement was also reduced by conducting the interview at a place and time convenient to the young person, and we minimized and simplified the questions asked to prevent additional cognitive challenges.

The main risk was that participants were depressed, and the areas probed in the interview could make them uncomfortable or distressed. A.K.T. reviewed patient notes prior to recruitment to check the level of risk and was able to liaise with the young person's lead clinician if concerns arose. The young person was receiving ongoing support from the specialist CFS/ME service, and we also notified the patient's general practitioner (GP) of their participation in the study.

The researcher was supported by a clinical team with extensive experience of managing the patient group and had rapid access to a senior member of the team if needed during the interview. We devised a policy for what to do if a young person was acutely distressed or at risk of harm, although it was never necessary to use it.

Method in Action

We conducted semi-structured interviews with nine young people with CFS/ME and co-morbid low mood. Eight of the nine participants were female, and their ages ranged from 13 to 17 years.

Young people described a complicated relationship between their fatigue symptoms and their

mood. Although most thought that their CFS/ME occurred first and caused their depression due to activity restriction and lack of independence, they also felt that there was a somewhat cyclical relationship between their fatigue and mood. Being unable to get involved in enjoyable activities due to fatigue provoked negative emotions including low mood, and often their negative cognitions around their symptoms worsened both mood and CFS/ME. Young people also described a loss of the person they used to be, and a changed role within their social environments, whether with friends, family, or school. It was challenging to negotiate these environments due to their CFS/ME, and this often led to difficult emotions and difficulty managing their CFS/ME symptoms. In addition, a lack of understanding and awareness of this “invisible illness” was highlighted by many participants. Young people found different treatment approaches helpful or unhelpful—approaches discussed included activity management, CBT, medication, and additional supportive networks in school or with other people with CFS/ME. Most participants were keen to try anything to help manage their symptoms but there was no unitary approach to treatment that young people found valuable, suggesting that individualized approaches should be developed and utilized.

Lessons Learned and Recommendations

The experience of conducting this qualitative study with this patient group identified a number of challenges, the most significant of which was difficulty recruiting. Other minor challenges included considering the specific challenges of interviewing young people (with and without parents) and how to best conduct home visits compared with telephone interviews. This section reflects on these challenges and highlights possible solutions. We have also noted more general recommendations for utilizing qualitative methodology. We have separated these into the different stages of methodology: study recruitment, interview preparation, interview techniques, dyadic interviewing, and post-interview reflection.

Recruitment Challenges

Recruitment presented a significant challenge, and it took more than a year to recruit nine patients. Although a researcher hand-searched patient notes to identify potentially eligible patients, included recruitment packs within those notes so that their clinician could recruit them, and notified the relevant clinician of the potential for that patient’s inclusion, it was nevertheless a very slow process.

We suggest creating a screening and inclusion flow chart to explore where difficulties with recruitment might originate. This could include documenting the number of eligible patients, which clinicians are approaching patients about the study, how many eligible patients receive a

recruitment pack, and how many join the study. It was difficult to tell whether the slowness with recruitment was due to clinicians forgetting, running out of time, not wanting to or feeling able to ask patients whether they wanted to participate, or whether the young people themselves did not want to participate.

If the problem lay primarily with clinicians not recruiting, this could be mitigated by engaging clinicians with the study design at its early stages, for example, by inviting them to contribute to the writing of the protocol or topic guide. It is possible that if clinicians feel more engaged with the study, they will be more likely to remember and participate in recruitment. In addition, as a visiting researcher, building a rapport with the clinical team may also help them to associate the study with a specific researcher and make them more willing to contribute. For studies where sampling is reliant on independent clinicians (rather than researchers themselves), these techniques may reduce delays in recruitment.

On the contrary, if the greater challenge lay in young people being reluctant to participate, it is important to identify this. Young people faced a double burden of fatigue symptoms and low mood, which could have made them less likely to feel able to or want to participate. It may be possible that there is a demographic difference between those who participate and those who do not—for example, if only those young people who are recovering or less depressed participate, we may miss young people who are more severely affected who could have different opinions that could alter the results. This could mean the study did not include a varied sample, so it is vital to record the details of all the young people who are eligible for the study and are offered a recruitment pack, not just those who become participants.

Interview Preparation

Involving healthy “controls” in the study design and topic guide development, as we did through discussion with a Young Persons’ Advisory Group (YPAG), can be extremely useful. The YPAG reviewed the information sheets and consent forms and had the opportunity to comment on our protocol and an early draft of the topic guide. The YPAG made a number of suggestions that we incorporated, including offering home visits so as to reduce the burden of travel costs, flexibility in how information was communicated, and the option that young people could either read the information from the patient information sheet or discuss it on the phone. The YPAG also recommended texting the young person and/or their parents the day before the interview to confirm that it was still convenient for the interview to take place. Finally, they suggested that participants should be offered a copy of the article once published. They also made suggestions about the topic guide; they felt that asking about the social and interpersonal challenges attached to having CFS/ME and low mood would be important for

young people.

We asked participants to complete a HADS questionnaire before the interview, explaining that this would guide some of the discussion in the interview. Providing information about the interviews in advance could mitigate some of the cognitive effort and difficulty associated with involvement in the interview itself, which is helpful for participants with CFS/ME and depression or may experience cognitive dysfunction as part of their symptom burden. It may also give the young people a better understanding of what to expect during the interview process, which may alleviate some of the nerves associated with having a researcher visit them. However, we did not send the complete topic guide because we wanted to ensure that participants did not prepare answers that they felt we would want to hear, and to try and enable open and honest responses to the questions requiring more introspection. We felt that this balance would help to ensure that young people felt prepared and knew what to expect from the interview, but would not feel that they had to over-prepare for a topic guide provided. It also enabled us to follow lines of conversation that opened up naturally within the interview rather than restricting the discussion to carefully edited questions and answers.

Interview Techniques

Patients with more complex presentations can be slightly more challenging to interview: these young people all had CFS/ME and low mood, which can make participation in research more challenging. This may be due to depression causing a lack of motivation to answer questions, due to CFS/ME's physical symptoms resulting in difficulty participating, or due to the cognitive dysfunction of CFS/ME (sometimes called "brain fog" by young people) and depression limiting young people's ability to process and answer questions. It is therefore necessary to be willing to take time to rephrase questions if necessary, and wait for them to consider and verbalize their answer rather than rushing through the interview. If the participant's answer is unclear, clarify it with them in a curious and respectful manner.

Because of the young people's age, and because of the potential physical and cognitive limitations of their illness, awareness of language used is crucial. Questions should be simplified, and a researcher must be skilled enough to be able to reword and reframe questions to enable all the participants to be asked the questions in the topic guide, without leading the participant toward a specific answer. We initially felt that there may need to be different approaches to interviewing young people of different age groups, and questions may need to be simplified further for participants at the lower end of the age bracket compared with those at the higher end, but in practice, this was not necessarily the case. This may be because many of the young people had been unwell for a significant length of time, and it is possible that their

experience of having a chronic illness had resulted in a quicker maturation in terms of self-reflection than their contemporaries without CFS/ME and low mood.

We did note that there was a slight change in young people's social priorities as they aged; older participants placed more of an emphasis on challenges faced in school than younger participants who worried more about friends. This was likely not statistically significant, particularly given our small sample size, but awareness of apparent shifts in priorities is an advantage of qualitative research and helped guide further interviews. In addition, this inductive approach to the interviews enabled us to add other questions, particularly focusing on school and social media support systems.

Most of our interviews were conducted in person in the participant's own home. Interviewing a vulnerable participant in their own environment offers security and flexibility for the young person, as they are somewhere comfortable to them. It is important to be aware of the power dynamics inherent in conducting interviews, especially if there is a significant age gap between the interviewer and participant. The interviewer is naturally in a position of power, not only because they are older and more experienced but also because they know what questions will be covered and because they can direct the interview. This can potentially make the participant uncomfortable and make it hard for them to explain their feelings or be open and candid about their experiences. However, interviewing the participant in a place of their choosing may alleviate this power difference—although there is still a difference in knowledge and experience, the comfort of being at home can make participants feel more confident and safe, whereas the interviewer is in a place they are unfamiliar with and are a guest in the participant's space.

One of our interviews was conducted on the phone. Although this method has benefits such as ease and simplicity (particularly if it is difficult to travel to meet the participant), there are potentially quite significant negative aspects to this technique. If you cannot see the participant, it can be challenging to respond appropriately to them as you cannot see their facial expressions or communicate non-verbally. A pause can mean that the participant is thinking, or that they do not want to answer, or that they are distressed, but it is impossible to judge this without being able to see them. This can potentially limit the depth and detail of the interview, and can mean that assumptions may be made about what the participant means because you cannot see their facial expressions when they speak.

However, it may be possible to strike a balance between the time investment required in visiting a patient at home and the ease (but potential communication difficulties) of speaking on the phone. This could potentially be done by using videoconferencing tools such as Skype. Young

people appear to find this less intrusive and feel more in control of the interaction, while the researcher still has a face-to-face interaction with them, albeit through a screen.

Dyadic Interviewing

Young people were reassured that they could be interviewed with a parent present or alone, and this was respected. Although the presence of a parent can enable a shy or nervous participant to speak more comfortably, it is often beneficial, for at least part of the interview, to interview the young person alone. This presence of a parent can introduce a power and/or family dynamic, which may result in the child naturally falling into a passive role and deferring to or falling into agreement with the parent/carer. The parent may interrupt, correct, or answer for the child. Interviewers should be skilled in using silence within the interview; however, this may feel alien to a parent, who may feel compelled to step in. We noted these types of interaction in our parent–child interviews:

Interviewer: Do you think that there would be any other treatments that would be helpful in managing this better?

Young person: I don't know ... because, like, we've been told that there's not many ...

Parent: They said about relaxation, to help you with your sleeping.

Interviewer: Yeah.

Parent: That's what [therapist name] was gonna work with you about, in therapy and that.

Social desirability is another issue to consider when interviewing the young person with their parent/carer present. Young people may have answered questions in a manner that they felt would be viewed as more favorable by their parents or carers; for example, they may have been reluctant to disclose negative behaviors or negative opinions about family dynamics. This issue was pertinent for our interviews, which covered sensitive subjects such as mood and the impact illness had on the family:

Interviewer: Yeah. Do you worry, do you feel upset about the effect it's had on your family?

Young person: Yeah.

Interviewer: I know it's a difficult question with your mum there.

We found that certain strategies cultivated an environment where young people felt empowered to participate in interviews alone for at least part of the discussion. Directly contacting young

people above the age of 16, rather than communication via the parent (unless indicated otherwise by the young person), can be helpful. Mentioning sole interviews from the very outset can also establish this expectation. For young people who want parental support, the researcher can suggest that a section of the interview is carried out alone once rapport had been established and once the participant feels comfortable with the interview situation.

We also reflected on ways in which parents/carers enhanced the interview process. For anxious individuals, parent/carer support can be helpful providing reassurance and confidence. For younger participants or if cognitive dysfunction is a prominent feature, the parent can help to prompt gaps in memory (which the young person can then elaborate on) and reframe questions to ensure that their child has understood. When relevant to the research question, a dyadic interview can help illuminate important relationships through joint narratives and through studying interactions. In our interviews, parent-carer interactions contributed to our theme about changing roles with family and friends. For example, the following parent-child exchange highlights the family dynamics and illuminated relationship with friends:

Parent: She hasn't been out for about four weeks, five weeks. I mean today she came out with me but that was the first time really.

Child: Yeah. And I prefer to be with you. Rather than my friends.

Parent: Cos she doesn't have to explain anything to me. If we're in town or something she'll just say, "I've got to go home" and we'll just say OK. We know, whereas her mates don't get that. Even with walking on crutches it's difficult, isn't it?

Child: The weekend before I got my crutches, that's what sent me down with my muscles in my legs, cos I was out with my friends and they walked the whole way round [location]. And I was out from, I was only going out for an hour but I ended up going out from half four, about three hours, and by the time I got back I'd done so much walking I'd torn the tendons in my knees. And when I told them they were like, "oh, sorry." And it was like, "do you see now that I can't walk that far?"

In dyadic interviewing, it is important to enable the young person's voice to be heard. This can be done explicitly by outlining this expectation, giving positive reinforcement to the family when the young person is encouraged to speak, and tactfully redirecting the focus of the conversation to young person if the parent becomes dominant in the interview. The interviewer can also use less direct methods, using body language and positioning to direct the questions at the child rather than the parent. Where individuals are seated in the room may be an important consideration.

On reflection, it could have been interesting to conduct dyadic interviews with participants and their friends. This may have increased insight and provided alternative perspectives about the impact of CFS/ME on friendships, but may be challenging for participants if they feel that their friends do not understand their illness.

After the Interview

Field notes can be helpful in recording any immediate thoughts after the interview. These notes are made by the researcher describing their impressions of the participant's behavior, body language and other features of the interview, to provide meaning and context to the transcription. For example, if a participant's facial expressions contradict their words, it is useful to note this down to benefit your analysis. In addition, if an interview brings up any strong emotions in you as the researcher, reflecting on this can benefit you personally.

We posted copies of the published articles to all the young people who took part in the study. Offering this to participants can help them feel more included in the process of writing and analyzing, and is a lovely way to thank them for their involvement.

Finally, reflecting on the methodology used, as we have done in this case study, can be as valuable as analyzing the results in terms of impact on your future work.

Conclusion

We wanted to understand more about the experiences of young people with CFS/ME and low mood. We chose to use qualitative methods to do this. Through this, we were able to successfully gain insight into young people's views on the relationship between fatigue and low mood, the impact of illness on quality of life, why they felt low mood developed, and their feelings on a variety of treatment strategy. Utilizing suggestions made by the YPAG at the stage of designing the research, and offering significant flexibility with interviews for young people, enabled successful interviews. However, we also encountered a number of difficulties, including with recruitment and the specific challenges of interviewing young people alone and with parents. Reflection on the strengths and limitations of our methodology is vital in ensuring that future research with this patient group succeeds.

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Exercises and Discussion Questions

1. What are the ethical dilemmas surrounding the involvement of young people in research?
2. What are the strengths and limitations of using semi-structured interviews in qualitative methodology? What other methods could have been used?
3. We commented on power dynamics when discussing doing interviews in the participants' homes. Can you think of other advantages and disadvantages to interviewing patients at home?
4. Imagine you are one of the participants. What sorts of experiences or feelings would you feel comfortable sharing and what would you not? Would this change if you had a parent in the room?

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